

Engagement Report for Clinical Commissioning Policies

Unique Reference Number	1827
Policy Title	Ablative surgery, moulage technique brachytherapy and surgical reconstruction (AMORE) for head and neck soft tissue sarcoma in children and young people
Lead Commissioner	Rupi Dev
Clinical Reference Group	Children and Young People's Cancer Services
Which stakeholders were contacted to be involved in policy development?	A policy working group (PWG) was established in line with NHS England's standard methods.
	The draft policy proposition was sent to the following groups for comment:
	 Members of the Children and Young People's (CYP) Cancer Clinical Reference Group (CRG); and Registered stakeholders of the CYP Cancer CRG.
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	The relevant major professional membership groups for children's and young people's cancer services – i.e., Children's Cancer and Leukaemia Group (CCLG), Teenage and Young Adult's Cancer (TYAC) and the Royal College of Nursing (CRN) - are members of the CYP Cancer CRG and were invited to comment. Responses were received from both CCLG and TYAC.
	The Royal College of Paediatrics and Child Health are registered stakeholders for the CYP Cancer CRG and were asked to comment on the draft policy proposition during stakeholder testing; no response was received from the organisation.
Which stakeholders	Responses were received from CCLG and TYA. In addition, 21 other responses were received from registered stakeholders including both CLIC Sargent and Sarcoma UK.

have actually been involved?	
Explain reason if there is any difference from previous question	Not applicable.
Identify any particular stakeholder organisations that may be key to the policy development that you have approached that have yet to be engaged. Indicate why?	None identified
How have stakeholders been involved? What engagement methods have been used?	The draft policy proposition was distributed to stakeholders via email for a period of two weeks of stakeholder testing, in preparation for public consultation. Stakeholders were asked to submit their responses via email, using a standard response and in line with NHS England's standard processes for developing clinical commissioning policies. Stakeholder testing asked the following questions: It is proposed that highly specialised products will go for period of public consultation. Please select the consultation level that you consider to be most appropriate. (6 weeks or up to 12 weeks) Do you have any further comments on the proposed changes to the document? If Yes, please describe below, in no more than 500 words, any further comments on the proposed changes to the document as part of this initial 'sense check'. Please declare any conflict of interests relating to this document or service area.
What has happened or changed as a	No changes have been made to the policy proposition as a result of stakeholder feedback.

result of their input?

There were 23 responses to stakeholder testing in total. No respondents supported the policy proposition and all recommended that the commissioning position be re-evaluated.

Stakeholders raised the following issues:

- Although stakeholders agreed that the evidence base was limited, they commented that the evidence review did demonstrate that AMORE treatment was associated with fewer adverse events with no differences in failure free survival, overall survival or health related quality of life.
- In addition, stakeholders felt that given the patient population that would eligible for treatment (i.e. a small and highly select patient group) large randomised control trials would not be carried out and it would be unlikely that any stronger information would be published for this treatment.
- One stakeholder provided reference to a paper published in 2019 (after the Evidence Review) which in their opinion demonstrated the benefits of AMORE.
- The individual components of the AMORE treatment (e.g. surgery, radiotherapy and reconstructive surgery) are already routinely commissioned by NHS England and form part of the standard care pathway for these patients. Some stakeholders queried therefore why AMORE treatment was deemed to not be effective.
- Stakeholders raised that AMORE treatment is considered to be cost neutral in comparison to the current available treatments for children and young people with head and neck sarcoma.
- Stakeholders recommended that the benefit of AMORE treatment be considered from a quality of life and family perspective. Current treatment for patients is delivered over a long period of time, however, AMORE treatment is delivered over a much shorter time period; a shorter treatment time would mean less time for the child to take off school and less disruption to the lives of families.

These comments have been reviewed by the PWG. Although the PWG are supportive of the comments raised by stakeholders, they note that on review of the clinical evidence, Clinical Panel deemed that "the strength of evidence was insufficient to support a for routine clinical commissioning policy position". An Evidence Report has been completed for the additional reference provided by a stakeholder, however, this is would not have met the criteria set out in the PICO and therefore does not affect the findings of Clinical Panel.

It is important to note that the decision to proceed a policy for not routine commissioning is based on clinical effectiveness and

	therefore cost impact analysis is not considered until later in the policy development process.
AM	All stakeholders (including CRG members and registered stakeholders) will be notified when the draft policy proposition goes out to public consultation.
What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement?	Of the 23 responses received to stakeholder testing, 15 respondents recommended that the policy could undergo a public consultation period of up to 6 weeks; 2 respondents recommended a 12 week public consultation and the remaining respondents (6) did not specify a time duration. Based on this feedback, the PWG is recommending a 6 week public consultation period.